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## Primary care experiences of adults reporting learning disability: a probability sample survey

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**Primary care experiences of adults reporting learning disability:  
a probability sample survey**

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**Primary care experiences of adults reporting learning disability:  
a probability sample survey**

**Abstract**

**Background**

Adults with learning disability face multiple adversities, but evidence on their needs and primary care experiences is limited.

**Aim**

To compare the characteristics and primary care experiences of adults reporting learning disability with those who did not.

**Design and setting**

An analysis of the 2022 General Practice Patient Survey, a national probability sample survey conducted in 2022 with people registered with NHS primary care in England.

**Method**

This analysis reports descriptive profiles, weighted and with 95% confidence intervals. Logistic regression models adjusting for gender, age, ethnicity, and area-level deprivation compared experiences of adults reporting learning disability with those who did not.

**Results**

Survey participants comprised 623,157 people aged 16 or older, including 6,711 reporting learning disability. Adults reporting learning disability were more likely to be male, younger, of mixed or multiple ethnicities, and live in more deprived areas. All chronic conditions included in the survey were more common in adults reporting learning disability, especially

reported sensory, neurodevelopmental, neurological, and mental health conditions. Adults reporting learning disability were twice as likely to have a preferred GP, and less likely to find their practice's website easy to navigate. They were also less likely to have confidence and trust in their healthcare professional, or feel their needs were met.

## **Conclusion**

Adults reporting a learning disability had a higher likelihood of chronic health conditions. Their reported experiences of primary care indicate that despite recent initiatives to improve services offered, further adaptations to the consistency and ease of access to primary care is needed.

## **Keywords**

Primary care, Learning disability, Epidemiology

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### **How this fits in**

Adults with a diagnosis of learning disability are at increased risk for a range of mental and physical health conditions, with a significantly reduced life expectancy compared to the general population. To our knowledge, this is the largest study of long-term conditions and primary care experiences among adults who report having learning disability. They report heightened rates for a wide range of chronic health conditions, and are more likely to express a preference for a particular GP, whilst being less likely to report confidence and trust in their healthcare professional, or their needs being met.

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## Introduction

Learning disability (LD) is defined by the World Health Organisation as a neurodevelopmental condition, characterised by significant limitations in intellectual functioning (approximately  $\geq 2$  standard deviations below the mean on standardized testing) and adaptive behaviour (conceptual, social, and practical skills), with onset during the developmental period.<sup>1</sup> There are approximately 1.5 million people with LD in England, representing around 2.5% of the population,<sup>2</sup> though only a fraction of these people are listed on their general practice's learning disability register.<sup>3</sup>

People with LD experience high rates of co-occurring mental illness, with Mazza et al.<sup>4</sup> reporting a pooled meta-analysis prevalence estimate of 33.6% (95% CI 25.3-43.1) for any psychiatric disorder among adults and adolescents with LD (from constituent eligible studies where LD was determined by case register identification or psychiatric interview).

Furthermore, adults with LD are at significantly higher risk of having a wide range of physical health conditions, including epilepsy, constipation, visual impairment, hearing impairment, and asthma.<sup>5</sup> The 2022 Learning from Lives and Deaths – people with a LD and autism (LeDeR) report describes a median age of death of 62.9 years for both adult males and adult females with LD in England (compared to 86.1 years for adult females and 82.6 for adult males without LD in the general population<sup>6</sup>), with 42% of deaths deemed avoidable.<sup>7</sup>

Despite their high level of clinical need, people with LD and/or autistic people, experience significant barriers to accessing primary care, including challenges to effective communication with healthcare professionals, a lack of accessible information, fear and embarrassment, long waiting times, and a lack of knowledge of LD among some healthcare professionals.<sup>8</sup> Such factors can lead to unmet healthcare needs in this patient group, such as reduced uptake of cervical cancer screening.<sup>9</sup> Furthermore, some people with LD, particularly those with mild LD, may not be known to clinical services, despite potentially having significant healthcare needs.<sup>10</sup>

Under the UK Equality Act 2010,<sup>11</sup> public sector organisations have a statutory requirement to make reasonable adjustments to ensure that their services are equally accessible to people with LD. Furthermore, these adjustments should be made proactively, rather than simply reacting under circumstances where patients encounter difficulties. There is additionally a legal accessible information standard, which requires National Health Service (NHS) and

adult social care organisations to provide information in a form that they can understand.<sup>12</sup> NHS England, a government organisation who provide leadership in the delivery of publicly funded NHS services across England,<sup>13</sup> cited LD as a priority in their 2019 NHS Long Term Plan,<sup>14</sup> with goals to tackle causes of morbidity and preventable death, and improve understanding of the needs of people with LD across the NHS.

NHS England commissions the national General Practice Patient Survey (GPPS) to provide evidence to support healthcare improvement for process measures of care quality. It is an annual cross-sectional postal survey of adults registered with a GP practice in England. The questionnaire asked of survey participants covers a wide range of demographic, social and health-related factors.<sup>15</sup>

Understanding the needs of the population reporting LD, rather than solely relying on those with a clinical diagnosis, is necessary for identifying how current models of healthcare do and do not meet their needs. In this analysis of the 2022 GPPS we aimed to examine the characteristics and primary care experiences of adults reporting LD, compared with those who do not, in England.

## **Methods**

### *GPPS 2022 Sampling*

The 2022 GPPS was conducted by Ipsos MORI, with the sample drawn from patients registered with GP practices in England between 10<sup>th</sup> January to 11<sup>th</sup> April 2022.<sup>16</sup> The sampling frame comprised those aged 16 and over (hereafter referred to as ‘adults’) with a valid NHS number and continuously registered with an NHS GP practice in England for at least 6 months, with samples from each practice stratified by age, gender, and postcode.<sup>16</sup> Over 2.47 million individuals were selected at random and had questionnaires mailed to their registered home address; 719,137 questionnaires were completed, representing a 29.1% response rate.<sup>15,16</sup> No data were collected on whether the intended addressee or a proxy (such as a carer) completed or supported the sampled patient to complete the questionnaire. Weights were developed by the survey contractor adjusting for sampling design and known patterns of non-response so that the achieved sample was representative of the GP-registered population.<sup>15,16</sup> Methodological detail for GPPS 2022, including the questionnaire, is

available.<sup>16</sup> Individual-level GPPS data were provided via a data sharing agreement with NHS England.

### *Learning disability identification*

An item on whether the survey respondent has learning disability was first introduced in the 2016 GPPS, as a stand-alone question.<sup>17</sup> For the 2022 GPPS,<sup>15</sup> the question asked: ‘Which, if any, of the following long-term conditions do you have?’, with ‘a learning disability’ as one of the response options, a similar approach to that used to identify people with LD in Scotland’s census.<sup>18</sup> Consequently, participating adults were required to self-report whether or not they think or know or believe or have been told they have a learning disability. Some respondents with a learning difficulty (referred to as a developmental learning disorder in ICD-11<sup>19</sup>), defined as having ‘a reduced intellectual ability for a specific form of learning,’<sup>20</sup> such as seen with dyslexia and dyspraxia, rather than LD, may have erroneously checked this item. There was no objective independent test within the survey to determine where this had occurred, and this issue is discussed further in the section on study limitations in the discussion. A binary coded variable was derived identifying those reporting LD and those who did not. Participants who did not provide a valid response were excluded from all analyses. Written descriptions of the groups reporting LD and not reporting LD are summarised in Table 1.

### *Demographic and health survey items*

Self-completed social and demographic items covered age, ethnicity, gender, transgender history, sexual identity, religion, caring responsibilities and smoking status. Socioeconomic items included participant reported employment status. and neighbourhood deprivation based on the Index of Multiple Deprivation quintile of the participant’s home address were included in the survey data.

Self-reported chronic health conditions were captured using a multiple-choice question and included: dementia; arthritis/musculoskeletal problems; autism; visual impairment; breathing condition; cancer (last 5 years); hearing impairment; diabetes; heart condition; high blood pressure; kidney or liver disease; mental health condition; neurological condition; stroke (affecting your day-to-day life); and another long-term condition or disability. A subsequent question on ‘long COVID’ (described as experiencing symptoms more than 12 weeks after first having COVID-19) was also included in our analyses.

### *Patient experience survey items*

The survey also included questions on participants' self-reported experiences of primary care services, using Likert scale response options. Items covered five broad domains: 1) overall experience, 2) before trying to make an appointment, 3) access, 4) continuity, and 5) communication. We categorised responses as positive or negative, producing a binary classification in line with the GPPS National Report.<sup>15</sup> Question wording and categorisation of responses are outlined in Supplementary Table S1.

### *Missing data*

Participants with missing data for long-term conditions were excluded from the analyses. Models adjusted for age, gender, ethnicity, and deprivation, for which missingness varied between 0.1% and 2.0%; thus, complete case analysis was performed.

### *Statistical analysis*

All results report unweighted sample counts alongside weighted proportions with 95% confidence intervals.

Participant characteristics are described for those reporting LD and those who did not. Weighted percentage point differences (ppd) are additionally reported, to enable comparisons between adults reporting LD from those who did not.

To examine differences in chronic health conditions between those reporting LD and those who did not, logistic regression models adjusting for age, ethnicity, gender and area-level deprivation (IMD quintile) were fitted to return adjusted odds ratios (aOR) with 95% CIs and p-values. Differences in the occurrence of long-term conditions between the two groups by age were investigated through the incorporation of an interaction effect between age and LD status. The marginal probability of each long-term condition by LD status and age was calculated and are presented graphically.

A similar approach was taken to compare the primary care experiences of adults reporting LD with those who did not. GP practice cluster information was not available, however robust standard errors were used to allow for some heteroscedasticity (heterogeneity of variance) in patient experiences across GP practices.

### *Sensitivity analysis*

We performed a sensitivity analysis which excluded patients who reported having dementia or autism from the analysis of experiences of primary care as these conditions were the long-term conditions found to have the highest adjusted odds ratios for adults reporting LD compared to those who did not (see Table 2). These conditions were only excluded for the sensitivity analyses, but not for other analyses reported in this article. In a second sensitivity analysis, we ran the analysis of experiences of primary care using different comparator groups, first comparing to those reporting no long-term health conditions and second comparing to those reporting at least one other long-term health condition.

## **Results**

### *Frequency of reported learning disability*

A total of 6,711 of the 623,157 participants included in the analyses self-reported LD, yielding a weighted proportion estimate of 1.8% (95% CI 1.7 to 1.9) of the sample. The 70,900 (9.9%) participants with missing data for long-term conditions were excluded from these analyses, as well as a further 25,080 (3.9%) participants with missing age, gender, ethnicity, or deprivation information.

### *Demographic characteristics*

Table S2 summarises the demographic characteristics of all survey respondents, as well as stratified by self-reported LD status. Adults reporting LD were more likely to describe their gender as male or non-binary, and to describe themselves as gay or lesbian, bisexual, or other. Those reporting LD were also younger (with higher proportions in 16–24-year and 25–34-year age groups), less likely to identify as being of Asian or Asian British ethnicity, and more likely to identify with no religion. Adults reporting LD were less likely to report having parental responsibility for a child in their household, and more likely to report having no unpaid caring responsibilities for other persons. In terms of employment status, they were less likely to report being in full-time work, and more likely to report being in full-time education, unemployed, or permanently sick or disabled. They were also more likely to be living at an address in the most deprived neighbourhoods.

### *Long-term conditions*

Table 2 shows the reported occurrence of long-term health conditions and long COVID in adults reporting LD compared to those who do not, after adjusting for age, gender, deprivation, and ethnicity. All 16 conditions had significantly higher odds of being reported by adults reporting LD compared to those who did not so describe themselves.

Figure 1 depicts differences in marginal probability of long-term conditions between those reporting LD and those who did not by age. The additional likelihood of self-identified autism in adults reporting LD is much greater in younger age groups, and declines with older age groups. Other conditions show an increased difference in marginal probabilities across middle age groups compared to extreme of age, such as arthritis, breathing conditions, diabetes, and self-reported mental health conditions.

#### *Experiences of primary care*

Table 3 shows the responses to patient experience question items. While for some question items no significant differences were found, several distinct differences with respect to their experiences of primary care were identified.

There were no significant differences between adults reporting LD and those who did not with respect to their overall experience of both their GP practice, as well as making an appointment.

Prior to making an appointment, adults reporting LD were more likely to report that they had spoken to a pharmacist, called an NHS helpline, and contacted or used another NHS service. However, they were less likely to have used either an NHS or non-NHS online service, tried to treat themselves, or tried to get information or advice elsewhere. No significant difference was identified with respect to asking for advice from friends or family prior to making an appointment.

For question items on access and continuity, adults reporting LD were more likely to find the receptionists at the GP practice helpful, be satisfied with the GP appointment times, be satisfied with the appointment offered, and have a preferred GP. However, they were less likely to find the GP practice's website easy to navigate. No significant differences were identified in relation to being offered an in-person appointment at their own GP practice, or being able to see or speak to their preferred GP.

For question items on communication, adults reporting LD were less likely to report having confidence and trust in healthcare professionals, and having their needs met. No significant

differences were identified with respect to being involved in decisions about care and treatment, or having their mental health needs recognised and understood.

After excluding participants reporting autism or Alzheimer's disease or other cause of dementia within a separate sensitivity analysis, the findings for patient experiences of primary care were unchanged, except a slight reduction in odds of having a preferred GP (aOR 1.90 compared to aOR 2.08) (Supplementary Table S3). When using different comparator groups, odds of overall positive experiences were higher than respondents with other long-term conditions whilst measures of communication were worse than respondents with no long-term conditions (Supplementary Table S4).

## **Discussion**

### *Summary*

In this study we report the characteristics and primary care experiences of adults reporting LD in England. Adults reporting LD are more likely to describe themselves as male, younger, non-religious, have no unpaid caring responsibilities, be in full-time education, unemployed, or permanently sick or disabled, and live in the most deprived neighbourhoods. They also report heightened rates of a wide range of chronic health conditions. With respect to primary care experiences, they are more likely to report difficulties using their GP practice's website, which provides a barrier to accessing primary care support. They are also more likely to have a preferred GP, though less likely to report confidence and trust in their healthcare professional, or their needs being met.

### *Strengths and limitations*

This study benefits from a large sample size of 6,711 adults reporting LD, and a comparator group of 616,446 adults completing the same survey questionnaire. The stratified probability approach helps additionally ensure that the study population is representative of adults registered with GP practices across England.

The survey requirement of adults reporting LD themselves is a strength but also a limitation because we have no objective test of participants to formally confirm such a diagnosis. Some may have a learning difficulty (referring to a specific domain of reduced intellectual functioning, for example dyslexia or dyspraxia<sup>20</sup>) rather than LD, which are terms that are

sometimes confused with one another.<sup>21</sup> However, data obtained on people with LD through such an approach has previously been reported in the research literature,<sup>22</sup> and reporting of such findings serve to give this marginalised patient group a voice. Furthermore, a formal diagnosis of LD is not a requirement to satisfy the definition of disability under the terms of the UK Equality Act 2010 (though medical evidence of the impact of the person's impairment is required).<sup>23</sup> Furthermore, some adults with LD might have required support from a carer (or 'proxy') in order to complete the survey, which could have influenced replies. Whilst many adults with mild LD (who represent the majority of people with LD<sup>24</sup>) could complete the survey with carer support, those with moderate to profound LD would be generally unlikely to be able to provide meaningful answers to many of the survey question items, even with carer support. This may have led to the LD survey respondent population being skewed towards those with milder LD. Another possibility is that for some adults with moderate to profound LD, their surveys may have been completed by their caregiver, and not be necessarily entirely representative of the patients' own experiences, though carers can express their own views about how they feel the person with LD they care for felt, based on their knowledge of them. This is preferable to the exclusion of such carer responses, which would risk only receiving survey responses relating to adults with milder forms of LD, compromising the generalisability of the data.

The accessibility of surveys for people with LD can be enhanced through multiple approaches, including involving them in question development, pilot testing of questions with a group of people with LD, and adding visual cues to the survey to provide added context.<sup>25</sup> Furthermore, the list of long-term conditions that were enquired about on the survey were limited, with certain conditions particularly relevant to people with LD, such as attention deficit hyperactivity disorder and epilepsy, not being included. Additionally, the 2022 GPPS overall had a response rate of 29.1%,<sup>15</sup> and the characteristics of respondents may not be representative of the pool of patients from which they were sampled, though the weighting helps partially address this issue.

#### *Comparison with existing literature*

An analysis of data from Scotland's census, similarly based on participants' self-/proxy-reporting of LD, previously reported increased representation of people with LD among male and younger age groups, consistent with the findings reported here, though data on other demographic characteristics, such as ethnicity, religion, and sexuality, were not reported.<sup>22</sup>

The elevated rates of chronic health conditions among adults reporting LD are consistent with previous findings, including related to mental illness,<sup>22, 26</sup> autism,<sup>27</sup> and physical health conditions.<sup>22, 28</sup> Previous qualitative research on improving primary care access for people with LD has described primary care interfaces as being ‘misaligned with the needs of people with learning disabilities’, with a GP commenting on a lack of accessible information online for this patient group.<sup>29</sup> Development of such accessible information may be most helpful when it is tailored to their individual patient’s needs, rather than developed with all people with LD in mind.<sup>30</sup> Additionally, such information needs to be also available for people with LD for whom English is not their first language. Furthermore, a literature review<sup>31</sup> reported that the health information needs of people with LD are being inadequately met. These findings are in line with our analysis, where adults reporting LD were less likely to report their needs being met, and find the GP practice’s website easy to use. Relatedly, people with LD are less likely to have essential digital skills,<sup>32, 33</sup> as well as being less likely to use the internet, or own a computer or smartphone.<sup>34</sup> Thus, there is an increased risk of people with LD having difficulties accessing primary care, particularly for practices where the internet represents the conventional means of booking an appointment. Additionally, whilst the GPPS has included a question item relating to having LD for several years, to the best of our knowledge this is the first journal article reporting national survey data on the primary care experiences of adults reporting LD.

#### *Implications for research and/or practice*

The survey findings about actions taken by adults reporting LD prior to making an appointment can inform targeted public health interventions for this group. For example, pharmacists may represent an invaluable point of intervention for adults with LD given their increased tendency to speak to them prior to making an appointment. There is a need to improve accessibility of practice websites for adults with LD, perhaps through patient and public involvement in website development and accessibility evaluations. More granular data is required to better understand why adults reporting LD are less likely to have confidence and trust in their healthcare professional, and feel that their needs were met. Such approaches could include a more targeted survey specifically for adults reporting LD, as well as semi-structured interviews and qualitative research, with additional carer involvement.

Our findings also have implications for primary care practice in England, in relation to the annual learning disability health checks. This is a government incentivised scheme, whereby

NHS GPs are paid to conduct assessments of people with LD aged  $\geq 14$  years, with a view to ‘identifying previously unrecognised health needs, including those associated with life-threatening illnesses.’<sup>35</sup> The finding that people with reported LD are more likely to have a preferred GP would support an approach where patients are given flexibility to choose who conducts their annual health check wherever possible. Continuity of care with a preferred GP may lead to greater uptake and engagement in future health checks. Furthermore, public health promotion of annual health checks, both at a local GP practice level, as well as regional and national levels, could be informed by the demographic characteristics of people with LD, such as targeting deprived neighbourhoods, where this patient group are more likely to reside. Additionally, based on the findings of people with LD being more likely to report their needs not being met, the annual health check could itself represent an ideal opportunity to also ensure that areas of priority importance for the patients themselves are identified and addressed wherever possible. However, in order to provide such adjustments on a national scale, GPs need to be well supported, including having longer consultation times where required,<sup>36</sup> to provide such a service.

For future versions of the GPPS, an easy-read version of the survey could be considered, with simplified terminology used in the survey questions, and pictures accompanying the questions. However, such an approach may compromise the ability to compare the findings for adults with and without LD (as the question wording would differ), and make year-on-year trend comparisons. Furthermore, there are mixed findings with respect to the accessibility value of adding accompanying illustrations to questions.<sup>37</sup> It would however be helpful to collect further information on LD, including whether the respondent has a clinical diagnosis, their severity of LD, and whether their carer assisted them in completing the survey. The person completing the questionnaire should also be asked if they are the person to whom it was addressed, and if not, their relationship with that person (e.g., paid carer or family member).

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**Ethical approval** This analysis did not require ethical approval as it represents an analysis of previously collected data.

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## References

- 1 World Health Organization. *ICD-11 for Mortality and Morbidity Statistics*. Geneva: World Health Organization; 2018.
- 2 House of Commons Library. *Learning disabilities: health policies*. 2023; <https://researchbriefings.files.parliament.uk/documents/SN07058/SN07058.pdf> (accessed 26 Jun 2024).
- 3 NHS England. *Health and Care of People with Learning Disabilities, Experimental Statistics 2022 to 2023*. 2023; <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2022-to-2023> (accessed 26 Jun 2024).
- 4 Mazza MG, Rossetti A, Crespi G, *et al*. Prevalence of co-occurring psychiatric disorders in adults and adolescents with intellectual disability: A systematic review and meta-analysis. *J Appl Res Intellect Disabil* 2020; **33**: 126-38.
- 5 Cooper S, McLean G, Guthrie B, *et al*. Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis. *BMC Fam Pract* 2015; **16**: 1-11.
- 6 Office for National Statistics. *National life tables – life expectancy in the UK: 2018 to 2020*. 2021; <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/bulletins/nationallifetablesunitedkingdom/2018to2020#:~:text=Across%20the%20UK%2C%20life%20expectancy,years%20for%20females%20in%20Northern> (accessed 26 Jun 2024).
- 7 King's College London. *Learning from Lives and Deaths - People with a learning disability and autistic people (LeDeR) report for 2022*. 2023; <https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-2022-v2.0.pdf> (accessed 26 Jun 2024).
- 8 Doherty AJ, Atherton H, Boland P, *et al*. Barriers and facilitators to primary health care for people with intellectual disabilities and/or autism: an integrative review. *BJGP open* 2020; **4**(3).
- 9 Brown HK, Plourde N, Ouellette-Kuntz H, *et al*. Brief report: cervical cancer screening in women with intellectual and developmental disabilities who have had a pregnancy. *J Intellect Disabil Res* 2016; **60**: 22-27.
- 10 Shemtob L, Ramanathan R, Courtenay K. Learning disability registers: known unknowns and unknown unknowns. *Br J Gen Pract* 2021; **71**: 153-154.
- 11 Legislation.Gov.UK. *Equality Act 2010*. 2024; <https://www.legislation.gov.uk/ukpga/2010/15/contents> (accessed 26 Jun 2024).

- 12 Public Health England. *Reasonable adjustments: a legal duty*. 2020; <https://www.gov.uk/government/publications/reasonable-adjustments-a-legal-duty/reasonable-adjustments-a-legal-duty> (accessed 26 Jun 2024).
- 13 NHS England. *What we do*. 2024; <https://www.england.nhs.uk/about/what-we-do/> (accessed 26 Jun 2024).
- 14 NHS. *The NHS Long Term Plan*. 2019; <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf> (accessed 26 Jun 2024).
- 15 Ipsos MORI. *GP Patient Survey: National report 2022 survey*. 2022; [https://www.gp-patient.co.uk/downloads/2022/GPPS\\_2022\\_National\\_report\\_PUBLIC.pdf](https://www.gp-patient.co.uk/downloads/2022/GPPS_2022_National_report_PUBLIC.pdf) (accessed 26 Jun 2024).
- 16 Ipsos MORI. *GP Patient Survey 2022: Technical Annex 2022*. 2022; [https://www.gp-patient.co.uk/downloads/2022/GPPS\\_2022\\_Technical\\_Annex\\_PUBLIC.pdf](https://www.gp-patient.co.uk/downloads/2022/GPPS_2022_Technical_Annex_PUBLIC.pdf) (accessed 26 Jun 2024).
- 17 GP Patient Survey. *Surveys, reports and materials*. 2024; <https://gp-patient.co.uk/surveysandreports-10-16> (accessed 26 Jun 2024).
- 18 Gov.UK. *Scotland's Census Household Questionnaire*. 2022; <https://www.scotlandscensus.gov.uk/media/mecf4qa4/scotlands-census-2022-household-questionnaire.pdf> (accessed 26 Jun 2024).
- 19 World Health Organisation. *6A03 Developmental learning disorder*. 2024; <https://icd.who.int/browse/2024-01/mms/en#2099676649> (accessed 26 Jun 2024).
- 20 Public Health England. *Learning disability - applying All Our Health*. 2023; <https://www.gov.uk/government/publications/learning-disability-applying-all-our-health/learning-disabilities-applying-all-our-health> (accessed 26 Jun 2024).
- 21 Mencap. *Learning difficulties*. 2024; <https://www.mencap.org.uk/learning-disability-explained/learning-difficulties> (accessed 26 Jun 2024).
- 22 Hughes-McCormack LA, Rydzewska E, Henderson A, *et al*. Prevalence of mental health conditions and relationship with general health in a whole-country population of people with intellectual disabilities compared with the general population. *BJPsych Open* 2017; **3**: 243-8.
- 23 Citizens Advice. *Check if you're disabled under the Equality Act*. 2024; <https://www.citizensadvice.org.uk/work/discrimination-at-work/dealing-with-discrimination-at-work/checking-if-its-discrimination/check-if-youre-disabled-under-the-equality-act-work/> (accessed 26 Jun 2024).
- 24 Emerson E, Hatton C. *Estimating Future Need for Adult Social Care for People with Learning Disabilities in England*. 2008; [https://eprints.lancs.ac.uk/id/eprint/21049/1/CeDR\\_2008-6\\_Estimating\\_Future\\_Needs\\_for\\_Adult\\_Social\\_Care\\_Services\\_for\\_People\\_with\\_Learning\\_Disabilities\\_in\\_England.pdf](https://eprints.lancs.ac.uk/id/eprint/21049/1/CeDR_2008-6_Estimating_Future_Needs_for_Adult_Social_Care_Services_for_People_with_Learning_Disabilities_in_England.pdf) (accessed 26 Jun 2024).

- 25 Friedman C, Spassiani NA. Making Survey Research Accessible for People with Intellectual and Developmental Disabilities. In: Bennett, G., Goodall, E. (eds) *The Palgrave Encyclopedia of Disability*. London: Palgrave Macmillan; 2024.
- 26 Cooper SA, Smiley E, Morrison J, *et al.* Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *Br J Psychiatry* 2007; **190**: 27-35.
- 27 Brugha TS, Spiers N, Bankart J, *et al.* Epidemiology of autism in adults across age groups and ability levels. *Br J Psychiatry* 2016; **209**: 498-503.
- 28 Liao P, Vajdic C, Trollor J, *et al.* Prevalence and incidence of physical health conditions in people with intellectual disability—a systematic review. *PLoS One* 2021; **16**: e0256294.
- 29 Wigham S, Bourne J, McKenzie K, *et al.* Improving access to primary care and annual health checks for people who have a learning disability: a multistakeholder qualitative study. *BMJ Open* 2022; **12(12)**: e065945.
- 30 Chinn D, Homeyard C. Easy read and accessible information for people with intellectual disabilities: Is it worth it? A meta-narrative literature review. *Health Expect* 2017; **20(6)**: 1189-1200.
- 31 Alshammari M, Doody O, Richardson I. Barriers to the access and use of health information by individuals with intellectual and developmental disability IDD: a review of the literature. *2018 IEEE International Conference on Healthcare Informatics (ICHI)* 2018:294-298.
- 32 Department for Digital, Culture, Media & Sport. *Digital Lifeline: A qualitative evaluation*. 2022; <https://www.gov.uk/government/publications/digital-lifeline-a-qualitative-evaluation/digital-lifeline-a-qualitative-evaluation#:~:text=Alongside%20lower%20levels%20of%20access,or%20memory%20disability%20do%20not> (accessed 26 Jun 2024).
- 33 Gov.UK. *Essential Digital Skills Framework*. 2018; [https://assets.publishing.service.gov.uk/media/5b9246d4e5274a4236952309/Essential\\_digital\\_skills\\_framework.pdf](https://assets.publishing.service.gov.uk/media/5b9246d4e5274a4236952309/Essential_digital_skills_framework.pdf) (accessed 26 Jun 2024).
- 34 Ofcom. *Disabled users access to and use of communication devices and services*. 2019; <https://www.ofcom.org.uk/siteassets/resources/documents/research-and-data/multi-sector/access-and-inclusion/2018/research-summary-learning-disability.pdf> (accessed 26 Jun 2024).
- 35 Public Health England. *Guidance: Annual health checks and people with learning disabilities*. 2016; <https://www.gov.uk/government/publications/annual-health-checks-and-people-with-learning-disabilities/annual-health-checks-and-people-with-learning-disabilities> (accessed 26 Jun 2024).
- 36 Schäfer WL, van den Berg MJ, Groenewegen PP. The association between the workload of general practitioners and patient experiences with care: results of a cross-sectional study in 33 countries. *Hum Resour Health* 2020; **18**: 1-9.

37 Sutherland RJ, Isherwood T. The evidence for easy-read for people with intellectual disabilities: A systematic literature review. *J Policy Pract Intel* 2016; **13**: 297-310.

38 GP Patient Survey. *Contact us*. 2024; <https://www.gp-patient.co.uk/contact> (accessed 26 Jun 2024).

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Table 1: Summary of adults reporting LD and not reporting LD.

<b>Adults reporting LD</b>	<b>Adults not reporting LD</b>
<ul style="list-style-type: none"> <li>• Adults with a clinical diagnosis of LD who identify as having LD</li> <li>• Adults without a clinical diagnosis of LD who identify as having LD and who would meet diagnostic criteria for LD if subjected to clinical assessment</li> <li>• Adults without a clinical diagnosis of LD who identify as having LD and who would not meet diagnostic criteria for LD if subjected to clinical assessment</li> </ul>	<ul style="list-style-type: none"> <li>• Adults with a clinical diagnosis of LD who do not identify as having LD</li> <li>• Adults without a clinical diagnosis of LD who do not identify as having LD and who would not meet diagnostic criteria for LD if subjected to clinical assessment</li> <li>• Adults without a clinical diagnosis of LD who do not identify as having LD and who would meet diagnostic criteria for LD if subjected to clinical assessment</li> </ul>

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Table 2: Prevalence of long-term health conditions, by whether participant reports LD.

Long-term health condition	Total Respondents N=623,157			LD (Yes) N= 6,711			LD (No) N= 616,446			Logistic regression <sup>1</sup>		
	N	weighted % <sup>2</sup>	95% CI	N	weighted % <sup>2</sup>	95% CI	N	weighted % <sup>2</sup>	95% CI	aOR	95% CI	P-value
Alzheimer's disease or other cause of dementia	5,248	0.6	(0.6, 0.6)	217	1.9	(1.5, 2.2)	5,031	0.6	(0.5, 0.6)	9.33	(7.48, 11.64)	<0.001
Arthritis or ongoing problem with back or joints	151,982	17.5	(17.4, 17.6)	1,719	17.1	(16.0, 18.4)	150,263	17.5	(17.4, 17.6)	2.46	(2.23, 2.72)	<0.001
Autism	4,481	1.4	(1.3, 1.5)	1,287	25.3	(23.7, 27.0)	3,194	1.0	(0.9, 1.0)	18.44	(16.48, 20.63)	<0.001
Blindness or partial sight	10,784	1.4	(1.3, 1.4)	489	6.0	(5.3, 6.9)	10,295	1.3	(1.2, 1.3)	8.90	(7.66, 10.36)	<0.001
Breathing condition, such as asthma or COPD	79,399	11.3	(11.2, 11.4)	1,414	17.7	(16.5, 19.0)	77,985	11.1	(11.0, 11.3)	2.05	(1.87, 2.24)	<0.001
Cancer (diagnosis or treatment in the last 5 years)	29,032	3.2	(3.1, 3.2)	252	2.2	(1.8, 2.6)	28,780	3.2	(3.1, 3.2)	1.66	(1.38, 2.00)	<0.001
Deafness or hearing loss	52,501	5.9	(5.8, 5.9)	913	10.0	(9.0, 11.2)	51,588	5.8	(5.7, 5.9)	4.87	(4.26, 5.57)	<0.001
Diabetes	66,069	7.8	(7.7, 7.8)	978	8.7	(8.0, 9.5)	65,091	7.7	(7.7, 7.8)	2.28	(2.06, 2.54)	<0.001
Heart condition, such as angina or atrial fibrillation	50,449	5.6	(5.5, 5.6)	563	5.8	(5.1, 6.7)	49,886	5.6	(5.5, 5.6)	2.65	(2.24, 3.13)	<0.001
High blood pressure	143,318	15.9	(15.8, 16)	1,253	10.8	(10.0, 11.7)	142,065	16.0	(15.9, 16.1)	1.73	(1.56, 1.93)	<0.001
Kidney or liver disease	16,317	2.0	(2.0, 2.1)	373	3.7	(3.3, 4.3)	15,944	2.0	(2.0, 2.0)	3.10	(2.67, 3.60)	<0.001
Mental health condition	60,899	12.3	(12.2, 12.4)	2,763	41.0	(39.3, 42.7)	58,136	11.8	(11.7, 11.9)	3.88	(3.59, 4.20)	<0.001
Neurological condition, such as epilepsy	12,963	2.1	(2.0, 2.2)	811	11.4	(10.4, 12.4)	12,152	1.9	(1.9, 2.0)	6.89	(6.18, 7.67)	<0.001
Stroke (which affects your day-to-day life)	7,163	0.8	(0.8, 0.9)	231	2.2	(1.8, 2.7)	6,932	0.8	(0.8, 0.8)	5.83	(4.76, 7.14)	<0.001
Another long-term condition or disability	91,286	13.8	(13.7, 14.0)	1,949	26.3	(24.8, 27.8)	89,337	13.6	(13.5, 13.7)	2.67	(2.46, 2.89)	<0.001
Long COVID	24,751	4.8	(4.7, 4.8)	371	6.1	(5.3, 7.1)	24,380	4.7	(4.7, 4.8)	1.19	(1.01, 1.40)	0.033

<sup>1</sup>Adjusted for age, gender, deprivation, and ethnicity

<sup>2</sup>Weighted percentages are calculated using survey design and non-response weights by age, gender, geographic location, and GP practice.

Figure 1: Marginal probability of long-term health condition or disability over age groups, by whether participant reports LD.

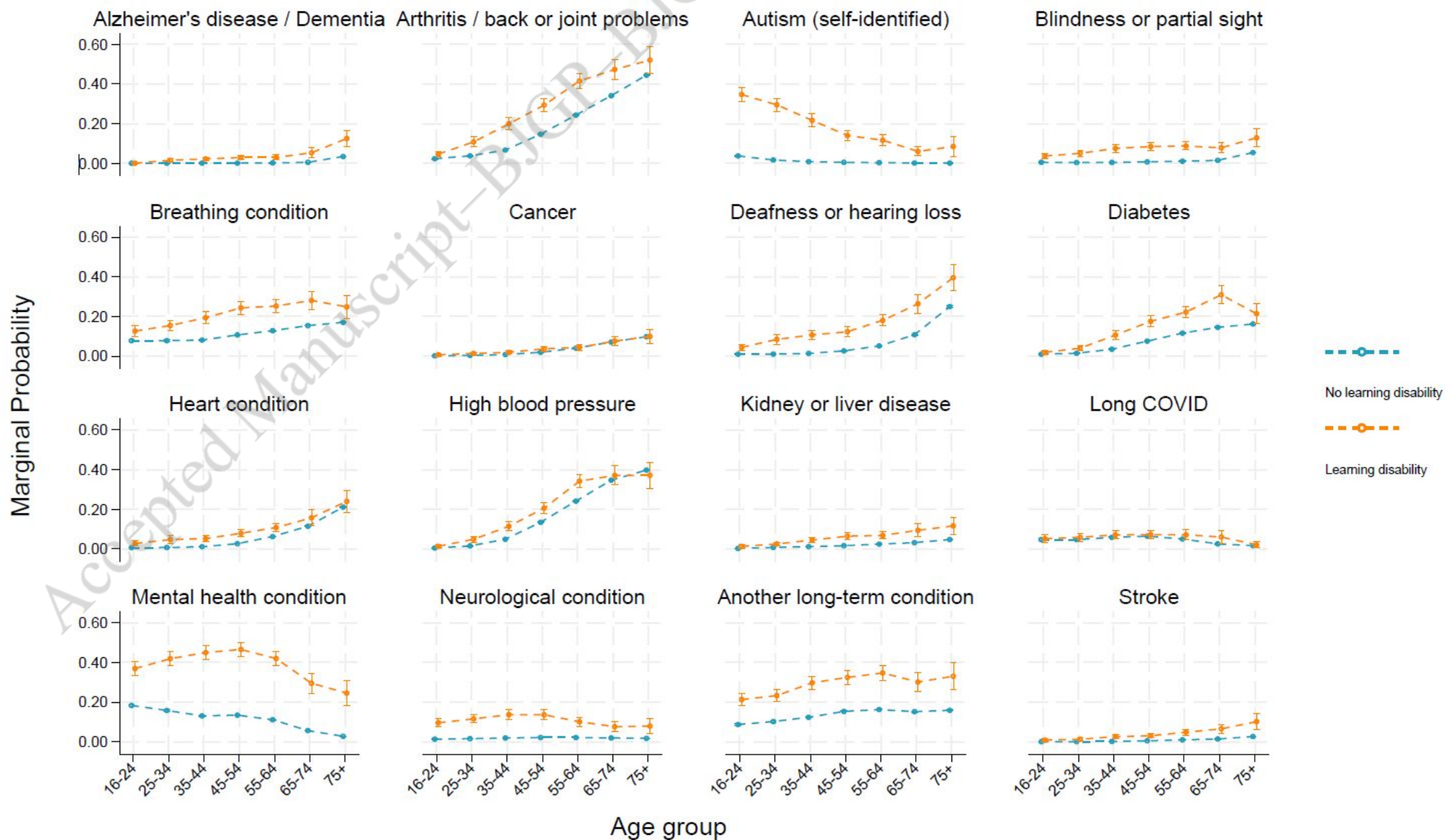


Table 3: Experience of primary care, by whether participant reports LD.

	Total Respondents N=623,157				LD (Yes) N= 6,711			LD (No) N= 616,446			Logistic regression <sup>1</sup>		
	Response %	N	Weighted % <sup>2</sup>	95% CI	N	Weighted % <sup>2</sup>	95% CI	N	Weighted % <sup>2</sup>	95% CI	aOR	95% CI	P- value
<b>Overall experience</b>													
Overall positive experience of GP practice	99.4	475,422	72.7	(72.5, 72.9)	4,769	69.5	(67.8, 71.1)	470,653	72.8	(72.6, 72.9)	1.07	(0.99, 1.16)	0.082
Overall positive experience of making appointment	93.9	355,207	56.4	(56.3, 56.6)	3,636	55.2	(53.4, 57.1)	351,571	56.5	(56.3, 56.7)	1.07	(1.00, 1.16)	0.067
<b>Before trying to make an appointment</b>													
Used an online NHS service	93.1	71,988	16.6	(16.5, 16.8)	933	18.1	(16.7, 19.7)	71,055	16.6	(16.4, 16.7)	0.79	(0.72, 0.88)	<0.001
Used a non-NHS online service	93.1	66,050	14.9	(14.7, 15.0)	716	13.8	(12.6, 15.1)	65,334	14.9	(14.7, 15.0)	0.69	(0.62, 0.77)	<0.001
Spoke to a pharmacist	93.1	93,091	16.5	(16.3, 16.6)	1,214	20.0	(18.6, 21.6)	91,877	16.4	(16.3, 16.6)	1.33	(1.20, 1.46)	<0.001
Tried to treat myself	93.1	140,586	26.7	(26.6, 26.9)	1,402	24.2	(22.6, 25.8)	139,184	26.8	(26.6, 27.0)	0.79	(0.72, 0.86)	<0.001
Called an NHS helpline	93.1	38,711	8.0	(7.9, 8.2)	706	11.5	(10.4, 12.8)	38,005	8.0	(7.9, 8.1)	1.24	(1.10, 1.40)	<0.001
Contacted or used another NHS service	93.1	24,744	4.9	(4.8, 5.0)	416	7.0	(6.2, 8.0)	24,328	4.9	(4.8, 4.9)	1.25	(1.09, 1.45)	0.002
Asked for advice from friends or family	93.1	96,162	21.4	(21.2, 21.5)	1,545	29.2	(27.5, 30.9)	94,617	21.2	(21.1, 21.4)	1.03	(0.94, 1.12)	0.534
Tried to get information or advice elsewhere	93.1	50,394	11.1	(11.0, 11.2)	568	10.8	(9.6, 12.1)	49,826	11.1	(11.0, 11.2)	0.76	(0.67, 0.87)	<0.001
<b>Access</b>													
Easy to use GP practice's website	54.2	233,960	67.2	(67.0, 67.5)	1,903	58.1	(55.7, 60.5)	232,057	67.4	(67.2, 67.6)	0.71	(0.65, 0.79)	<0.001
Easy to get through to someone on the phone	95.9	352,018	52.9	(52.7, 53.0)	3,608	51.8	(50.0, 53.6)	348,410	52.9	(52.7, 53.1)	1.02	(0.95, 1.10)	0.562
Found the receptionists at GP practice helpful	95.8	511,890	82.4	(82.2, 82.5)	5,218	79.8	(78.3, 81.3)	506,672	82.4	(82.3, 82.6)	1.10	(1.01, 1.21)	0.039
Satisfied with GP appointment times	84.0	314,871	55.3	(55.1, 55.5)	3,496	57.1	(55.2, 59.0)	311,375	55.3	(55.1, 55.5)	1.25	(1.16, 1.36)	<0.001
Satisfied with appointment offered	83.7	391,447	72.1	(71.9, 72.3)	3,987	72.8	(71.1, 74.5)	387,460	72.1	(71.9, 72.3)	1.17	(1.07, 1.28)	0.001
In-person appointment at own GP practice <sup>3</sup>	77.4	226,054	46.1	(45.9, 46.3)	2,229	47.6	(45.5, 49.7)	223,825	46.1	(45.9, 46.3)	1.04	(0.95, 1.13)	0.419
<b>Continuity</b>													
Have a preferred GP	93.7	280,260	43.1	(42.9, 43.3)	3,572	54.2	(52.3, 56.0)	276,688	42.9	(42.7, 43.1)	2.08	(1.93, 2.25)	<0.001
Able to see or speak to preferred GP <sup>4</sup>	38.2	111,203	43.4	(43.1, 43.7)	1,328	41.7	(39.1, 44.2)	109,875	43.5	(43.2, 43.8)	0.94	(0.85, 1.05)	0.275
<b>Communication</b>													
Involved in decisions about care and treatment	83.2	474,164	90.1	(90.0, 90.2)	4,921	86.9	(85.7, 88.1)	469,243	90.2	(90.0, 90.3)	0.92	(0.83, 1.03)	0.160
Had mental health needs recognised and understood	41.7	215,632	81.0	(80.8, 81.2)	3,816	79.0	(77.3, 80.6)	211,816	81.1	(80.8, 81.3)	0.99	(0.89, 1.10)	0.859
Confidence and trust in healthcare professional	92.1	541,619	93.3	(93.1, 93.4)	5,401	90.1	(89.0, 91.2)	536,218	93.3	(93.2, 93.4)	0.87	(0.77, 0.99)	0.030
Needs were met	92.3	534,101	91.1	(91.0, 91.2)	5,262	87.0	(85.7, 88.1)	528,839	91.2	(91.1, 91.3)	0.87	(0.78, 0.97)	0.015

<sup>1</sup>Adjusted for age, gender, deprivation, and ethnicity

<sup>2</sup>Weighted percentages are calculated using survey design and non-response weights by age, gender, geographic location, and GP practice.

<sup>3</sup>Base: Patient who accepted an appointment the last time they tried to book.

<sup>4</sup>Base: Patients with a preferred GP.

## Supplementary Tables

Table S1: Patient experience questions: wording and categorisation of responses

	Question	Positive/affirmative responses	Negative responses	Exclusions
<b>Overall experience</b>				
Overall positive experience of GP practice	Overall, how would you describe your experience of your GP practice?	‘Very good’ ‘Fairly good’	‘Neither good nor poor’ ‘Fairly poor’ ‘Very poor’	
Overall positive experience of making appointment	Overall, how would you describe your experience of making an appointment?	‘Very good’ ‘Fairly good’	‘Neither good nor poor’ ‘Fairly poor’ ‘Very poor’	
<b>Before trying to make an appointment</b>				
	Before you tried to get this appointment, did you do any of the following?			
Used an online NHS service		Used an online NHS service (including NHS 111 online)		
Used a non-NHS online service		Used a non-NHS online service, or looked online for information		
Spoke to a pharmacist		Spoke to a pharmacist		
Tried to treat myself		Tried to treat myself / the person I was making this appointment for (for example with medication)		
Called an NHS helpline		Called an NHS helpline, such as NHS 111		
Contacted or used another NHS service		Contacted or used another NHS service		
Asked for advice from friends or family		Asked for advice from a friend or family member		
Tried to get information or advice elsewhere		Tried to get information or advice elsewhere (from a non-NHS service)		
<b>Access</b>				
Easy to use GP practice's website	How easy is it to use your GP practice's website to look for information or access services?	‘Very easy’ ‘Fairly easy’	‘Not very easy’ ‘Not at all easy’	‘Haven't tried’
Easy to get through to someone on the phone	Generally, how easy is it to get through to someone at your GP practice on the phone?	‘Very easy’ ‘Fairly easy’	‘Not very easy’ ‘Not at all easy’	‘Haven't tried’
Found the receptionists at GP practice helpful	How helpful do you find the receptionists at your GP practice?	‘Very helpful’ ‘Fairly helpful’	‘Not very helpful’ ‘Not at all helpful’	‘Don't know’
Satisfied with GP appointment times	How satisfied are you with the general practice appointment times that are available to you?	‘Very satisfied’ ‘Fairly satisfied’	‘Neither satisfied nor dissatisfied’ ‘Fairly dissatisfied’ ‘Very dissatisfied’	‘I'm not sure when I can get an appointment’

Satisfied with appointment offered	Were you satisfied with the appointment (or appointments) you were offered?	‘Yes, and I accepted an appointment’	‘No, but I still took an appointment’ ‘No, and I did not take an appointment’	‘I was not offered an appointment’
In-person appointment at own GP practice <sup>1</sup>	What type of appointment did you get?	‘...to see someone at my GP practice’	‘...to speak to someone on the phone’ ‘...to see someone at another general practice location’ ‘...to speak to someone online (for example on a video call)’ ‘...for a home visit’	
<b>Continuity</b>				
Have a preferred GP	Is there a particular GP you usually prefer to see or speak to?	‘Yes, for all appointments’ ‘Yes, for some appointments but not others’	‘No’	‘There is usually only one GP in my GP practice’
Able to see or speak to preferred GP <sup>2</sup>	How often do you see or speak to your preferred GP when you would like to?	‘Always or almost always’ ‘A lot of the time’	‘Some of the time’ ‘Never or almost never’	‘I have not tried’
<b>Communication</b>				
Involved in decisions about care and treatment	During your last general practice appointment, were you involved as much as you wanted to be in decisions about your care and treatment?	‘Yes, definitely’ ‘Yes, to some extent’	‘No, not at all’	‘Don’t know / doesn’t apply’
Had mental health needs recognised and understood	During your last general practice appointment, did you feel that the healthcare professional recognised and/or understood any mental health needs that you might have had?	‘Yes, definitely’ ‘Yes, to some extent’	‘No, not at all’	‘I did not have any mental health needs’ ‘Did not apply to my last appointment’
Confidence and trust in healthcare professional	During your last general practice appointment, did you have confidence and trust in the healthcare professional you saw or spoke to?	‘Yes, definitely’ ‘Yes, to some extent’	‘No, not at all’	‘Don’t know / doesn’t apply’
Needs were met	Thinking about the reason for your last general practice appointment, were your needs met?	‘Yes, definitely’ ‘Yes, to some extent’	‘No, not at all’	‘Don’t know / can’t say’

<sup>1</sup>Base: Patient who accepted an appointment the last time they tried to book (To the question: were you satisfied with the appointment (or appointments) you were offered? Responded ‘Yes, and I accepted an appointment’ or ‘No, but I still took an appointment’).

<sup>2</sup>Base: Patients with a preferred GP (To the question: is there a particular GP you usually prefer to see or speak to? Responded ‘Yes, for all appointments’, or ‘Yes, for some appointments but not others’).

Table S2: Demographic characteristics of responders to the 2022 GPPS England, by whether participant reports LD.

Characteristics	Total Respondents N=623,157			LD (Yes) N= 6,711			LD (No) N= 616,446			Comparison, percentage point difference	
	N	unweighted % weighted % <sup>1</sup>	95% CI	N	unweighted % weighted % <sup>1</sup>	95% CI	N	unweighted % weighted % <sup>1</sup>	95% CI	Weighted PPD	95% CI
<b>Gender</b>	<b>623,157</b>	<b>100.0</b>		<b>6,711</b>	<b>100.0</b>		<b>616,446</b>	<b>100.0</b>			
Female	356,810	51.8	(51.6, 52.0)	3,182	37.6	(36.0, 39.2)	353,628	52.0	(51.8, 52.2)	-14.4	(-16.1, -12.8)
Male	263,985	47.7	(47.5, 47.9)	3,428	60.6	(59.0, 62.3)	260,557	47.4	(47.2, 47.6)	13.2	(11.6, 14.9)
Non-binary	1,286	0.3	(0.3, 0.4)	66	1.3	(0.9, 1.8)	1,220	0.3	(0.3, 0.3)	1.0	(0.5, 1.4)
Prefer to self-describe	1,076	0.2	(0.2, 0.3)	35	0.5	(0.3, 0.7)	1,041	0.2	(0.2, 0.2)	0.2	(0.0, 0.4)
<b>Gender matches sex registered at birth</b>	<b>615,596</b>	<b>98.8</b>		<b>6,506</b>	<b>96.9</b>		<b>609,090</b>	<b>98.8</b>			
Yes	612,501	99.3	(99.3, 99.3)	6,378	97.7	(97.1, 98.2)	606,123	99.3	(99.3, 99.4)	-1.6	(-2.1, -1.0)
No (transgender)	3,095	0.7	(0.7, 0.7)	128	2.3	(1.8, 2.9)	2,967	0.7	(0.6, 0.7)	1.6	(1.0, 2.1)
<b>Sexual identity</b>	<b>587,951</b>	<b>94.4</b>		<b>5,792</b>	<b>86.3</b>		<b>582,159</b>	<b>94.4</b>			
Heterosexual or straight	565,782	94.3	(94.2, 94.4)	5,139	87.7	(86.4, 88.8)	560,643	94.4	(94.3, 94.5)	-6.8	(-8.0, -5.5)
Gay or lesbian	9,475	2.5	(2.4, 2.6)	204	4.2	(3.5, 5.0)	9,271	2.4	(2.4, 2.5)	1.8	(1.0, 2.5)
Bisexual	7,243	2.1	(2.0, 2.1)	256	5.1	(4.3, 5.9)	6,987	2.0	(2.0, 2.1)	3.0	(2.2, 3.8)
Other	5,451	1.1	(1.1, 1.2)	193	3.1	(2.5, 3.8)	5,258	1.1	(1.0, 1.1)	2.0	(1.3, 2.6)
<b>Age</b>	<b>623,157</b>	<b>100.0</b>		<b>6,711</b>	<b>100.0</b>		<b>616,446</b>	<b>100.0</b>			
16 to 24	22,447	9.2	(9.0, 9.3)	1,058	27.4	(25.7, 29.2)	21,389	8.8	(8.7, 9.0)	18.6	(16.8, 20.3)
25 to 34	48,990	16.8	(16.6, 16.9)	1,374	30.9	(29.2, 32.6)	47,616	16.5	(16.3, 16.7)	14.3	(12.6, 16.1)
35 to 44	73,111	17.6	(17.5, 17.8)	1,144	17.4	(16.2, 18.6)	71,967	17.6	(17.5, 17.8)	-0.3	(-1.5, 1.0)
45 to 54	99,032	17.5	(17.3, 17.6)	1,099	11.5	(10.7, 12.4)	97,933	17.6	(17.5, 17.7)	-6.0	(-6.9, -5.2)
55 to 64	135,247	16.5	(16.4, 16.6)	1,147	8.3	(7.7, 9.0)	134,100	16.6	(16.5, 16.7)	-8.3	(-9.0, -7.7)
65 to 74	135,805	12.2	(12.1, 12.3)	558	2.7	(2.5, 3.1)	135,247	12.4	(12.3, 12.4)	-9.6	(-9.9, -9.3)
75 or over	108,525	10.3	(10.2, 10.4)	331	1.7	(1.5, 2.0)	108,194	10.4	(10.4, 10.5)	-8.7	(-9.0, -8.4)
<b>Ethnicity</b>	<b>623,157</b>	<b>100.0</b>		<b>6,711</b>	<b>100.0</b>		<b>616,446</b>	<b>100.0</b>			
White	524,894	82.5	(82.4, 82.7)	5,387	83.7	(82.5, 84.8)	519,507	82.5	(82.3, 82.6)	1.2	(0.0, 2.4)
Mixed or Multiple ethnic groups	8,955	2.0	(1.9, 2.0)	224	3.4	(2.8, 4.1)	8,731	2.0	(1.9, 2.0)	1.4	(0.8, 2.1)
Asian or Asian British	54,676	9.6	(9.5, 9.7)	602	7.3	(6.5, 8.1)	54,074	9.7	(9.5, 9.8)	-2.4	(-3.2, -1.6)
Black, Black British, Caribbean or African	23,337	3.8	(3.8, 3.9)	310	3.6	(3.1, 4.2)	23,027	3.8	(3.8, 3.9)	-0.2	(-0.8, 0.3)
Other ethnic group	11,295	2.0	(2.0, 2.1)	188	2.1	(1.7, 2.5)	11,107	2.0	(2.0, 2.1)	0.0	(-0.4, 0.5)
<b>Religion</b>	<b>601,323</b>	<b>96.5</b>		<b>6,237</b>	<b>92.9</b>		<b>595,086</b>	<b>96.5</b>			
No religion	180,422	38.1	(37.9, 38.3)	2,278	43.8	(42.0, 45.7)	178,144	38.0	(37.8, 38.2)	5.9	(4.0, 7.7)
Buddhist	4,103	0.7	(0.7, 0.8)	50	0.5	(0.4, 0.7)	4,053	0.7	(0.7, 0.8)	-0.2	(-0.4, 0.0)
Christian	354,933	50.2	(50.0, 50.3)	3,001	43.4	(41.6, 45.3)	351,932	50.3	(50.1, 50.5)	-6.8	(-8.7, -5.0)
Hindu	12,344	2.1	(2.0, 2.1)	107	1.2	(0.9, 1.5)	12,237	2.1	(2.0, 2.2)	-0.9	(-1.3, -0.6)

Jewish	3,552	0.5	(0.5, 0.5)	49	0.7	(0.5, 1.0)	3,503	0.5	(0.5, 0.5)	0.2	(0.0, 0.5)
Muslim	31,173	5.9	(5.8, 6.0)	500	6.3	(5.5, 7.1)	30,673	5.9	(5.8, 6.0)	0.4	(-0.4, 1.2)
Sikh	5,648	0.9	(0.8, 0.9)	60	0.6	(0.4, 0.9)	5,588	0.9	(0.8, 0.9)	-0.2	(-0.4, 0.0)
Other	9,148	1.7	(1.7, 1.8)	192	3.4	(2.8, 4.2)	8,956	1.7	(1.6, 1.7)	1.7	(1.1, 2.4)
<b>Parental responsibility for child in household</b>	<b>618,341</b>	<b>99.2</b>		<b>6,624</b>	<b>98.7</b>		<b>611,717</b>	<b>99.2</b>			
Yes	112,520	24.8	(24.7, 25.0)	787	11.8	(10.7, 13.0)	111,733	25.1	(24.9, 25.2)	-13.3	(-14.4, -12.1)
No	505,821	75.2	(75.0, 75.3)	5,837	88.2	(87.0, 89.3)	499,984	74.9	(74.8, 75.1)	13.3	(12.1, 14.4)
<b>Caring responsibilities due to health or old age</b>	<b>609,699</b>	<b>97.8</b>		<b>6,468</b>	<b>96.4</b>		<b>603,231</b>	<b>97.9</b>			
No	484,218	81.2	(81.1, 81.4)	5,360	83.9	(82.5, 85.1)	478,858	81.2	(81.1, 81.3)	2.7	(1.4, 4.0)
Yes, 1 to 9 hours/week	62,976	9.6	(9.5, 9.7)	434	7.3	(6.4, 8.3)	62,542	9.7	(9.6, 9.8)	-2.4	(-3.4, -1.4)
Yes, 10 to 49 hours/week	35,169	5.4	(5.3, 5.4)	336	4.7	(4.1, 5.4)	34,833	5.4	(5.3, 5.4)	-0.7	(-1.3, 0.0)
Yes, 50+ hours/week	27,336	3.8	(3.7, 3.8)	338	4.1	(3.6, 4.8)	26,998	3.8	(3.7, 3.8)	0.4	(-0.2, 1.0)
<b>Employment status</b>	<b>606,199</b>	<b>97.3</b>		<b>6,282</b>	<b>93.6</b>		<b>599,917</b>	<b>97.3</b>			
Full-time work	209,028	46.1	(45.9, 46.3)	993	19.1	(17.7, 20.7)	208,035	46.5	(46.4, 46.7)	-27.4	(-28.9, -25.9)
Part-time work	75,700	12.5	(12.4, 12.6)	541	8.7	(7.7, 9.7)	75,159	12.5	(12.4, 12.7)	-3.9	(-4.9, -2.9)
Full-time education	12,675	4.8	(4.7, 4.9)	571	13.9	(12.6, 15.4)	12,104	4.6	(4.5, 4.7)	9.3	(7.9, 10.7)
Unemployed	20,446	4.1	(4.0, 4.2)	948	16.1	(14.8, 17.5)	19,498	3.9	(3.8, 4.0)	12.2	(10.9, 13.6)
Permanently sick/disabled	29,663	4.6	(4.6, 4.7)	2,248	31.8	(30.2, 33.4)	27,415	4.2	(4.1, 4.2)	27.6	(26.0, 29.3)
Retired	213,907	20.6	(20.5, 20.7)	520	2.9	(2.6, 3.2)	213,387	20.9	(20.8, 21.0)	-18.0	(-18.3, -17.7)
Looking after family/home	28,014	4.5	(4.4, 4.6)	186	2.5	(2.1, 3.0)	27,828	4.6	(4.5, 4.6)	-2.0	(-2.5, -1.5)
Other	16,766	2.8	(2.7, 2.9)	275	5.0	(4.2, 5.9)	16,491	2.8	(2.7, 2.8)	2.2	(1.4, 3.1)
<b>Neighbourhood deprivation</b>	<b>623,157</b>	<b>100.0</b>		<b>6,711</b>	<b>100.0</b>		<b>616,446</b>	<b>100.0</b>			
1 - Most deprived	122,385	20.3	(20.2, 20.5)	2,368	33.1	(31.5, 34.8)	120,017	20.1	(19.9, 20.2)	13.1	(11.4, 14.7)
2	124,775	20.7	(20.5, 20.8)	1,610	24.3	(22.8, 25.8)	123,165	20.6	(20.5, 20.8)	3.7	(2.2, 5.2)
3	128,570	20.2	(20.0, 20.3)	1,188	17.8	(16.5, 19.1)	127,382	20.2	(20.1, 20.4)	-2.5	(-3.8, -1.1)
4	127,355	19.7	(19.5, 19.8)	891	13.8	(12.7, 15.1)	126,464	19.8	(19.7, 19.9)	-6.0	(-7.2, -4.7)
5 - Least deprived	120,072	19.1	(19.0, 19.3)	654	11.0	(10.0, 12.1)	119,418	19.3	(19.1, 19.4)	-8.3	(-9.4, -7.2)
<b>Smoking status</b>	<b>618,979</b>	<b>99.3</b>		<b>6,600</b>	<b>98.3</b>		<b>612,379</b>	<b>99.3</b>			
Never smoked	351,318	59.7	(59.5, 59.8)	4,199	68.0	(66.4, 69.6)	347,119	59.5	(59.3, 59.7)	8.5	(6.9, 10.2)
Ex-smoker	194,890	26.6	(26.4, 26.7)	1,105	12.6	(11.6, 13.7)	193,785	26.8	(26.7, 27.0)	-14.2	(-15.3, -13.2)
Occasional smoker	33,140	6.7	(6.6, 6.8)	507	8.1	(7.2, 9.1)	32,633	6.6	(6.5, 6.7)	1.5	(0.5, 2.4)
Regular smoker	39,631	7.1	(7.0, 7.2)	789	11.2	(10.1, 12.4)	38,842	7.0	(6.9, 7.1)	4.2	(3.1, 5.3)

<sup>1</sup>Unweighted percentages show proportion of non-missing responses; Weighted percentages are calculated using survey design and non-response weights by age, gender, geographic location, and GP practice.

Table S3: Experience of primary care, by whether participant reports LD: sensitivity analysis excluding patients with Alzheimer's disease or other cause of dementia or autism (excluding n=9,609 patients; 1.5%).

	LD (Yes) N= 5,276		LD (No) N= 608,272		Logistic regression <sup>1</sup>		
	Weighted % <sup>2</sup>	95% CI	Weighted % <sup>2</sup>	95% CI	aOR	95% CI	p-value
<b>Overall experience</b>							
Overall positive experience of GP practice	69.6	(67.7, 71.4)	72.8	(72.6, 73.0)	1.05	(0.96, 1.15)	0.259
Overall positive experience of making appointment	55.7	(53.6, 57.8)	56.5	(56.3, 56.7)	1.08	(0.99, 1.18)	0.066
<b>Before trying to make an appointment</b>							
Used an online NHS service	18.8	(17.0, 20.6)	16.5	(16.3, 16.7)	0.86	(0.76, 0.97)	0.012
Used a non-NHS online service	13.5	(12.2, 15.0)	14.9	(14.7, 15.0)	0.70	(0.61, 0.79)	<0.001
Spoke to a pharmacist	19.0	(17.3, 20.7)	16.4	(16.3, 16.5)	1.23	(1.10, 1.37)	<0.001
Tried to treat myself	23.1	(21.3, 24.9)	26.8	(26.6, 27.0)	0.74	(0.67, 0.82)	<0.001
Called an NHS helpline	11.9	(10.6, 13.5)	7.9	(7.8, 8.1)	1.31	(1.14, 1.51)	<0.001
Contacted or used another NHS service	6.7	(5.8, 7.8)	4.8	(4.7, 4.9)	1.22	(1.04, 1.44)	0.017
Asked for advice from friends or family	27.2	(25.3, 29.2)	21.1	(21.0, 21.3)	0.97	(0.88, 1.08)	0.627
Tried to get information or advice elsewhere	10.5	(9.1, 12.1)	11.1	(10.9, 11.2)	0.76	(0.65, 0.89)	0.001
<b>Access</b>							
Easy to use GP practice's website	56.7	(53.8, 59.5)	67.5	(67.2, 67.7)	0.67	(0.59, 0.75)	<0.001
Easy to get through to someone on the phone	50.9	(48.9, 53.0)	52.9	(52.7, 53.1)	0.99	(0.91, 1.07)	0.758
Found the receptionists at GP practice helpful	79.9	(78.2, 81.6)	82.5	(82.3, 82.6)	1.08	(0.97, 1.20)	0.150
Satisfied with GP appointment times	57.0	(54.8, 59.2)	55.3	(55.1, 55.5)	1.23	(1.13, 1.35)	<0.001
Satisfied with appointment offered	73.2	(71.1, 75.1)	72.1	(72.0, 72.3)	1.18	(1.07, 1.31)	0.001
In-person appointment at own GP practice <sup>3</sup>	48.0	(45.6, 50.4)	46.1	(45.9, 46.3)	1.06	(0.97, 1.17)	0.203
<b>Continuity</b>							
Have a preferred GP	52.3	(50.2, 54.4)	42.7	(42.5, 42.9)	1.90	(1.75, 2.07)	<0.001
Able to see or speak to preferred GP <sup>4</sup>	40.2	(37.5, 43.1)	43.3	(43.1, 43.6)	0.90	(0.80, 1.01)	0.085
<b>Communication</b>							
Involved in decisions about care and treatment	87.0	(85.6, 88.3)	90.2	(90.1, 90.3)	0.91	(0.80, 1.03)	0.140
Had mental health needs recognised and understood	78.3	(76.2, 80.3)	81.1	(80.8, 81.3)	0.94	(0.84, 1.06)	0.336
Confidence and trust in healthcare professional	90.3	(89.0, 91.4)	93.4	(93.3, 93.5)	0.86	(0.75, 0.99)	0.040
Needs were met	87.3	(85.9, 88.7)	91.3	(91.1, 91.4)	0.87	(0.77, 0.99)	0.039

<sup>1</sup>Adjusted for age, gender, deprivation, and ethnicity

<sup>2</sup>Weighted percentages are calculated using survey design and non-response weights by age, gender, geographic location, and GP practice.

<sup>3</sup>Base: Patient who accepted an appointment the last time they tried to book.

<sup>4</sup>Base: Patients with a preferred GP.

Table S4: Experience of primary care, by whether participant reports LD: sensitivity analysis using different comparator groups: (1) those with no other long-term health conditions and (2) those with at least one other long-term health conditions.

	LD (Yes) N=6,711		Comparator group 1: No other long-term conditions N=218,822		Comparator group 2: Another long-term condition N=397,624		Logistic regression (Comparator group 1) <sup>1</sup>			Logistic regression (Comparator group 2) <sup>1</sup>		
	Weighted % <sup>2</sup>	95% CI	Weighted % <sup>2</sup>	95% CI	Weighted % <sup>2</sup>	95% CI	aOR	95% CI	p-value	aOR	95% CI	p-value
<b>Overall experience</b>												
Overall positive experience of GP practice	69.5	(67.8, 71.1)	72.7	(72.4, 72.9)	72.8	(72.6, 73.1)	0.97	(0.90, 1.05)	0.497	1.21	(1.12, 1.31)	<0.001
Overall positive experience of making appointment	55.2	(53.4, 57.1)	58.1	(57.8, 58.5)	55.2	(54.9, 55.4)	0.95	(0.88, 1.03)	0.198	1.24	(1.14, 1.33)	<0.001
<b>Before trying to make an appointment</b>												
Used an online NHS service	18.1	(16.7, 19.7)	18.8	(18.6, 19.1)	14.8	(14.6, 15.0)	0.84	(0.76, 0.93)	0.001	0.74	(0.66, 0.82)	<0.001
Used a non-NHS online service	13.8	(12.6, 15.1)	16.7	(16.5, 16.9)	13.5	(13.3, 13.6)	0.74	(0.66, 0.82)	<0.001	0.63	(0.56, 0.70)	<0.001
Spoke to a pharmacist	20.0	(18.6, 21.6)	16.0	(15.7, 16.2)	16.8	(16.6, 16.9)	1.41	(1.28, 1.55)	<0.001	1.24	(1.12, 1.36)	<0.001
Tried to treat myself	24.2	(22.6, 25.8)	26.7	(26.4, 27.0)	26.8	(26.6, 27.1)	0.88	(0.81, 0.96)	0.005	0.68	(0.63, 0.75)	<0.001
Called an NHS helpline	11.5	(10.4, 12.8)	8.3	(8.1, 8.5)	7.7	(7.6, 7.9)	1.35	(1.20, 1.53)	<0.001	1.15	(1.01, 1.30)	0.029
Contacted or used another NHS service	7.0	(6.2, 8.0)	4.5	(4.4, 4.6)	5.1	(5.0, 5.2)	1.46	(1.27, 1.69)	<0.001	1.06	(0.92, 1.23)	0.417
Asked for advice from friends or family	29.2	(27.5, 30.9)	23.9	(23.6, 24.1)	19.2	(19.0, 19.4)	1.10	(1.00, 1.20)	0.041	0.94	(0.86, 1.03)	0.184
Tried to get information or advice elsewhere	10.8	(9.6, 12.1)	12.0	(11.8, 12.2)	10.4	(10.2, 10.5)	0.84	(0.73, 0.96)	0.008	0.66	(0.58, 0.76)	<0.001
<b>Access</b>												
Easy to use GP practice's website	58.1	(55.7, 60.5)	68.6	(68.2, 69.0)	66.4	(66.1, 66.7)	0.64	(0.57, 0.70)	<0.001	0.82	(0.74, 0.91)	<0.001
Easy to get through to someone on the phone	51.8	(50.0, 53.6)	54.6	(54.3, 54.9)	51.6	(51.3, 51.8)	0.92	(0.85, 0.99)	0.026	1.15	(1.07, 1.24)	<0.001
Found the receptionists at GP practice helpful	79.8	(78.3, 81.3)	82.0	(81.7, 82.2)	82.8	(82.6, 83.0)	0.98	(0.89, 1.08)	0.707	1.28	(1.16, 1.41)	<0.001
Satisfied with GP appointment times	57.1	(55.2, 59.0)	55.1	(54.8, 55.5)	55.4	(55.2, 55.6)	1.16	(1.07, 1.26)	<0.001	1.39	(1.28, 1.50)	<0.001
Satisfied with appointment offered	72.8	(71.1, 74.5)	73.4	(73.1, 73.7)	71.1	(70.9, 71.4)	1.01	(0.92, 1.10)	0.846	1.39	(1.27, 1.52)	<0.001
In-person appointment at own GP practice <sup>3</sup>	47.6	(45.5, 49.7)	49.7	(49.3, 50.0)	43.3	(43.0, 43.5)	0.86	(0.79, 0.94)	0.001	1.29	(1.19, 1.41)	<0.001
<b>Continuity</b>												
Have a preferred GP	54.2	(52.3, 56.0)	33.3	(33.1, 33.6)	50.6	(50.3, 50.8)	2.85	(2.64, 3.08)	<0.001	1.46	(1.35, 1.57)	<0.001
Able to see or speak to preferred GP <sup>4</sup>	41.7	(39.1, 44.2)	40.8	(40.3, 41.4)	44.9	(44.6, 45.2)	1.03	(0.92, 1.15)	0.613	0.87	(0.78, 0.97)	0.014
<b>Communication</b>												
Involved in decisions about care and treatment	86.9	(85.7, 88.1)	90.7	(90.5, 90.9)	89.8	(89.6, 90.0)	0.77	(0.68, 0.86)	<0.001	1.11	(0.99, 1.24)	0.081
Had mental health needs recognised and understood	79.0	(77.3, 80.6)	82.4	(82.0, 82.8)	80.2	(79.9, 80.5)	0.82	(0.74, 0.91)	<0.001	1.14	(1.03, 1.27)	0.015
Confidence and trust in healthcare professional	90.1	(89.0, 91.2)	93.9	(93.7, 94.0)	92.9	(92.8, 93.0)	0.68	(0.60, 0.77)	<0.001	1.13	(0.99, 1.28)	0.063
Needs were met	87.0	(85.7, 88.1)	91.5	(91.4, 91.7)	91.0	(90.8, 91.1)	0.70	(0.63, 0.79)	<0.001	1.08	(0.97, 1.21)	0.168

<sup>1</sup>Adjusted for age, gender, deprivation, and ethnicity

<sup>2</sup>Weighted percentages are calculated using survey design and non-response weights by age, gender, geographic location, and GP practice.

<sup>3</sup>Base: Patient who accepted an appointment the last time they tried to book.

<sup>4</sup>Base: Patients with a preferred GP.